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ABSTRACT

This first-person account discusses how a cochlear implant has allowed an individual with deafness to hear. It describes how cochlear implants function, the development of cochlear implants and who can benefit from the implants and to what extent. It also discusses how well people can hear with a cochlear implant. Factors strongly associated with success with an implant, such as duration of profound deafness and motivation, are addressed. The second part of the paper discusses opposition to cochlear implants by individuals with deafness who believe the implants are an insult and a threat to their culture. The devices, according to these opponents, represent a condemnation of deafness and an attempt to fix something that they do not consider in need of fixing. Historical reasons for the opposition to cochlear implants are explored, and the need for support groups of individuals with cochlear implants is urged. The final part of the paper discusses future advances and upgrades of cochlear implants. (Contains 11 references.) (CR)

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TURNED ON: COCHLEAR IMPLANTS FOR DEAF AND HARD-OF-HEARING PERSONS

A paper presented at the California State University "Technology and Persons with Disabilities" conference, March, 1998, Los Angeles.

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Introduction

The device within my ear that allows me to hear is a cochlear implant. It is the first effective artificial sensory organ, the result of one of the most rapid advances ever made in medical technology. In this paper, I will introduce you to the technology and how it works, give a bit of its history, and describe who can benefit from it and to what extent. I will also discuss a few issues that set this device apart from other technologies developed for persons with a disability. [1]

How a Cochlear Implant Works

Because my hair covers the transmitter resting on my scalp behind my ear, the only visible part of my system is normally a digital processor, a cigarette-pack sized box that I wear at my waist on a belt. A tiny electrode array made up of a bundled set of 22 platinum electrodes is implanted for a length of about 25 millimeters within my cochlea. The cochlea being like a piano, different parts of it are responsible for different pitches. As a result, when the nerve endings of my cochlea are stimulated in different spots according to messages sent by the processor, impulses are sent to my brain which are interpreted as sound at different frequencies. Table 1 lists the procedure by which a cochlear implant translates acoustic information into electrical impulses that are then perceived as sound by the brain.

The cycle of taking in sound, and converting it to electrical impulses to stimulate specified electrodes at specified intensities is quite rapid: it only takes 4 milliseconds to complete. Newer systems are even faster, sending information, for example, at a rate of 91,000 times per second.

Not surprisingly, before I received my cochlear implant, I was told to keep my expectations low. I was told that initially, voices might sound like cartoon characters. When I was first "turned on" after the surgery however, -- meaning my external equipment was programmed and switched on – and my audiologist spoke to me, he sounded not like Donald Duck or Mickey Mouse, but like Harpo Marx blowing whistles and squeezing horns. When he asked me how it sounded, I said it sounded awful, and I felt nauseous. But gradually, the sounds came together, and the whistles and

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horns started to sound like voices, and I realized that I was hearing far more in my environment than I ever remember hearing. In time, I also learned that what I thought were "whistles" at the end of plural nouns were the letter "s," a sound I don't remember ever hearing before. I started to understand voices better, first with lipreading, and then after a few months, even without lipreading, as I gradually became able to use the phone and understand some speech without any visual cues. This was something that I had not been able to do since childhood, as I grew up with a progressive sensorineural hearing loss that became profound by my early teens.

I have only 22 electrodes within my inner ear, and of course these few points of stimulation cannot completely replace the 15,000 ear hair cells that sense sound in the normal inner ear. But, the brain, even in adults, is quite plastic; we are all of us capable of adapting in ways that we would never dream possible.

A Bit of History

The history of the cochlear implant goes back to the late eighteenth century, when Alessandro Volta, the Italian physicist, experimented with an electric current to his ears. He attached two metal rods to active electric circuits and inserted one rod into each ear. He said he felt something like a blow to his head, then heard a noise that sounded like a boiling liquid. The results couldn't have been pleasant, and Volta didn't try the experiment again. Much later, in 1957, from France, came the first reports of an electrode successfully implanted on the auditory nerve, to give some sensation of sound to a deaf man.

Since that time, teams of engineers, scientists, doctors, and audiologists around the world have worked on developing sophisticated and powerful implant systems. The field is wonderfully interdisciplinary. At the beginning, however, it was also considered one of quackery. For example, in 1965, Dr. Blair Simmons of California submitted a paper to the American Otological Society outlining the first multiple electrode implant in a human, which he had performed in 1964. His paper was rejected then as being too controversial. Yet, in 1997, at the XVI World Congress of Otorhinolaryngology in Sydney, Australia, papers on cochlear implantation made up approximately 10% of the total number of presentations. Cochlear implants today are considered a proven, safe method of giving hearing ability to profoundly deaf adults and children, and some severely deaf adults as well.

Who are the Candidates for this Device?

Adults and children from about the age of two are generally considered candidates for the procedure if they are profoundly deaf in both ears, meaning a person would on the average, hear nothing softer than 90 decibels over the key frequencies of 500, 1000, and 2000 Hz. (A dog's bark, for example, is roughly at 80 decibels of intensity at a frequency around 500 Hz.; a baby's cry is roughly 60 decibels at 750 Hz.) These criteria are sometimes lowered for adults, and severely hearing impaired adults who cannot hear more than 40% of the key words and phrases in sentences given to them without lipreading may also be candidates. There are other criteria as well: the loss needs to be of sensorineural origin, the auditory nerve needs to be intact,[2] and the patient's motivation to hear and operate within a hearing milieu needs to be good.

There are about 20,000 people in the world who now hear with a cochlear implant, but this is a very small proportion of those who could potentially benefit. Profound hearing loss occurs in one in 1,000 children at birth, and one in 500 by the age of five.[3] Approximately one person in ten in the general population has some sort of hearing loss, and for roughly one person in one hundred the loss is severe or profound.[4] These people could be candidates for this little-known procedure that can allow the deaf to hear birdsong, symphonies, and speech.

How Well Do People Hear with a Cochlear Implant?

There is a confoundingly wide variation in individual performance with the same device. While my performance is better than was expected, I am an "average" performer: there are many who do much better or much worse. For example, in one study of performance reported in 1997, sixty-one adults were tested on their ability to understand sentences without lipreading six months after their equipment was turned on. Although the average score was 84% (i.e., they could understand 84% of key words and phrases), there was a very large range of success. Individuals scored anywhere between 24% and 100%. The range for performance on a more difficult test of monosyllabic words without lipreading was even greater. While the average result was an excellent 48%, individual performances ranged between a low of 8% and a high of 90%.[5]

Children, especially if they receive an implant early, and are given appropriate support, can do well with these devices. In a set of 100 unselected children and adolescents with multiple electrode implants in 1995, approximately 60% could understand a significant amount of speech without lipreading.[6] Approximately 30% were able to communicate freely using auditory input alone (with their implant devices). The researchers studying this group, however, were able to account for only 40% of the variance in speech perception scores by connecting individual scores with commonly used factors such as age at implantation, duration of profound hearing loss, pre-implant hearing ability, and type of hearing loss. There is still a lot that is unexplained when it comes to how well people do with their cochlear implants.

An Adaptive Technology Like No Other -- Significant Issues:

Poor Ability to Predict Individual Success; Wide Range of Performance

There are some factors that are strongly associated with success with an implant, such as duration of profound deafness, and motivation. Even so, surprises can result from conditions that are impossible to evaluate in advance, such as the placement of the electrode array relative to surviving neurons in the ear, and the health of the central auditory system in the brain. There are probably also some factors affecting success that no one has yet completely identified. It is difficult to predict how well people will do, and how quickly they will adapt. Success, however, is a subjective evaluation too. Some will be happy to just hear environmental sounds, others will be disappointed if they cannot participate in conference telephone calls.

The programs or strategies used for processing sound and for stimulating electrodes have become sophisticated, and there are many options that can be used by the audiologist in fitting or fine-

tuning the device for an individual. A few of the parameters that are determined for each individual are the threshold of the softest sound and the ceiling of the loudest comfortable sound sensed at each electrode site, the path of the electric current, which can be monopolar or bipolar, the stimulation mode, which can be simultaneous or sequential, and the number of electrodes activated.

More electrodes, and more technology, however, might not be the answer to improved success. Dr. Robert Shannon, director of Auditory Implant Research at the House Ear Institute in Los Angeles, claims that we may have reached a point of overkill in the technology of cochlear implants: he says that developers can provide many channels of less than optimum information with multiple electrodes, but haven't yet figured out how to adjust the fitting for a patient to deliver just a few channels of information optimally.[7] He warns that because we do not understand why the devices work as well as they do, and why there are such variations in results, we are in danger of running out of one of the key factors that has led to our success to date: "serendipity."

Dr. Shannon suggests that much of the variability in how well patients do may stem not only from personal differences, but also from the fact that some people are not fitted appropriately with their devices, and we do not yet know enough about how to custom-fit devices for each patient. Many audiologists with whom I have spoken agree with Dr. Shannon. They say their fittings of patients are often by trial and error, and they would benefit from more guidelines for what should be tried with certain patients. Much more research is needed, however, before they can do so.

Opposition to the Devices

Many people who belong to the Deaf culture, who use sign language as their primary means of communication are opposed to the devices, especially for children. They consider them an insult and a threat to their culture. The technology, according to these opponents, represents a condemnation of deafness, and an attempt to fix something that they do not consider in need of fixing. Instead, they are proud of their culture, which they have built around deafness. In defending that culture, a Canadian Deaf culture association has called the use of cochlear implants in children a form of ethnic purification and genocide, as well as emotional and mental abuse.[8] The hospital where I had my surgery performed in Toronto has been picketed by members of the Deaf culture, opposing the surgery in both adults and children.

In order to understand this opposition, we need to put it in historical context. Deaf persons throughout history have been persecuted and treated as inferiors. For example, in Europe, until the middle of the eighteenth century, deaf mutes were not even recognized as persons by the law. They were unable to marry or inherit property or receive an education (unless they managed somehow to be trained to speak). In England, although education for children was made compulsory in 1876, it was not until 1893 that deaf children were required to attend school. In North America, even in recent years, there have been cases where deaf persons have been improperly diagnosed as retarded or mentally ill, and placed in institutions. It is no wonder, then, that following the example of Black pride and gay pride, there is now a Deaf pride movement, for which opposition to cochlear implants has become a rallying point. There is not sufficient space in

this short paper to go into the manifestations and causes of this opposition (interested readers may wish to check out my book),[9] however, I believe that once more is known about the success of these devices and the low risk of surgery,[10] and professionals become more skilled in selecting appropriate candidates and advising them realistically about the benefits, the pendulum will swing back to the middle. The decision to receive a cochlear implant is a personal one to be made carefully by a deaf adult or the parents of a deaf child.

Users Supporting Users

More than most beneficiaries of medical or technological advances, cochlear implant recipients need each other. We will have questions about what it's like to hear with this prosthesis that no hearing professional, no matter how experienced, can answer in quite the same way as a deaf person who wears the device. And, we typically have a million questions before and after the surgery. Will the sounds be uncomfortable? (Yes and no.) Will everything be too loud? (Maybe.) Is it stressful? (It's exhilarating!) I don't like the sounds; is there something I can do? (Yes, encourage your audiologist to experiment with different settings.)

In answer to this need for support, groups have sprung up, many collected under the mother organization, Cochlear Implant Club International.[11] In addition there are some Internet discussion groups that serve as online support groups. Many deaf persons with the device also serve as mentors to new users, holding their hand and offering support. These mentors and groups empower patients, help them to be more assertive about their needs, and give them the tools to be better informed and more proficient users of the technology. Proficiency is not simply a matter of turning on a switch.

Upgrades

Some of the upgrades for this device consist of replacing processors with newer more advanced units, or loading new processing strategy software into existing processors. However, a key way in which this device differs from most adaptive technologies is that some upgrades will require surgery to replace the implanted components. The surgery does not come with a high risk and is commonly done on an outpatient basis in the U.S., but the device, surgery and follow-up care cost about U.S. $40,000. This is beyond the means of most recipients, who normally receive coverage for their initial device through health insurance or government funding. There are now available, however, newer, faster cochlear implants, with more flexible processing options that might provide better hearing for people with only slightly older devices. In order to take advantage of these advances, people with the older devices would need to have new surgery and new equipment. But, the group studies that show some benefit of newer devices over older multiple-electrode devices are very difficult to translate into guarantees of improvements for individuals. The factors affecting success are hard to nail down with absolute certainty, and deaf persons present with differing and complex mixtures of biological, psychological and social characteristics. Consequently it may be very difficult for deaf persons to obtain coverage for surgical upgrades other than to replace much older single-electrode devices with multiple-electrode devices.

Most surgeons are also reluctant to replace functioning devices with newer ones that might or might not provide more benefit. As one surgeon told me, he could be violating his Hippocratic oath to do no harm – a patient would not only be temporarily utterly deafened by the removal of a device, but he or she might also do worse with its replacement. Moreover, for children especially, there is the issue of keeping an ear "free" for future interventions such as ear hair cell regeneration, which might require an intact inner ear. The issue of upgrades is not a simple one, but the issue may become more clear as the technology matures, and as the ability of professionals to predict success also improves. In many ways, this technology is still in its infancy.

Where Do We Go from Here?

No doubt there will be changes on many fronts. Technologically, the devices will become more sophisticated, and new processing strategies will be developed that are even more effective than those of today. Surgically, the devices will become totally implantable and indeed at least two companies are currently working on such devices that will have no external parts. Clinically, therapists and audiologists will improve their ability to custom fit and fine-tune the settings for a person's cochlear implant to allow everyone to get the best benefit out of their devices. And finally, I hope to see a bridge to the Deaf culture built, so that cochlear implants will no longer be seen as a threat and an insult, but as powerful systems of adaptive technology that can help some deaf persons to adapt to a hearing milieu.

. . . It has now been four years since my cochlear implant was first turned on. The horns and whistles that I heard then now seem like normal hearing. I feel sometimes as if I have always heard this way, as if I always knew what the letter "s" sounded like, that plastic bags make a rustling sound, and that a pencil makes a scratching noise when I write with it on a piece of paper. I still discover new sounds, however, realizing what I have missed. Just last month, walking within my house, I stopped and listened: for the first time, I heard the soft rhythmic patter of rain on the roof.

Table 1: Cochlear Implant Processing Steps (for author's device):*

1. Sound is received by an microphone that rests over the ear like a behind-the-ear hearing aid.
2. Sound is sent from the microphone to the signal processor by a thin cable.
3. Signal processor translates the sound into electrical codes.
4. Codes are sent by a thin cable to the transmitter held to the scalp by its attraction to a magnet implanted beneath the skin.
5. Transmitter sends codes across the skin to a receiver/stimulator implanted in the mastoid bone.
6. Receiver/stimulator converts the codes to electrical signals.
7. Electrical signals are sent to the specified electrodes in the array within the cochlea to stimulate neurons.
8. Neurons send messages along the auditory nerve to the central auditory system in the brain where they are interpreted as sound.

* This is a description of how the author's implant system works. While the basic principles of operation are similar for all multichannel devices commercially available in 1998, the components

may vary in size and appearance, and certain components (e.g., the microphone and transmitter) may be combined. A behind-the-ear processor in clinical trials in several countries shrinks the size of the processor, moves it to ear level, and combines it with the microphone.

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Endnotes:

1. Portions of this paper have been adapted from my book, *Wired for Sound: A Journey into Hearing* to be published in the fall of 1998 by Trifolium Books, 238 Davenport Road, Suite 28, Toronto, Ontario Canada M5R 1J6. E-mail: trifoliu@ican.net
2. If the auditory nerve has been severed, there is a similar prosthesis that can be used, called an auditory brainstem implant, that bypasses the inner ear and auditory nerve. Results with it, however, are generally not as good as those with a cochlear implant.
3. The Listening Center at Johns Hopkins, *Bringing Sound to Life for Deaf Children* (brochure).
4. The Canadian Hearing Society, *Hearing Loss: Questions and Answers*, May 1991, p. 2; Canadian Hearing Society Bulletin CHS94102-05. The number of deaf persons in the United States, however, has been revised downward by the National Institute on Deafness and Other Communication Disorders (NIDCD) from 2 million "profoundly deaf" in 1988, to 421,000 who are "deaf in both ears" in 1994 (.18% of the population). The difference in the numbers reveals how statistics can be greatly affected by definitions of who is "deaf"; moreover, self-identification of the deaf in surveys can be unreliable. For estimates, see the current "NIDCD Fact Sheet: Statistics on Deafness and Hearing Disorders in the United States."
5. J. Muller et al., "Evaluation of Performance with the Combi 40 in Adults: A Multicenter Clinical Study," paper presented at the Fifth International Cochlear Implant Conference, New York, 1997.
6. R.C. Dowell et al., "Potential and Limitations of Cochlear Implants in Children," *Proceedings of the International Cochlear Implant, Speech and Hearing Symposium* (Melbourne, 1994).
7. R.V. Shannon, "Cochlear Implants: What Have We Learned and Where Are We Going?" *Seminars in Hearing* 17 (1996): 403-15.
8. Canadian Association of the Deaf, Press Release, January 25, 1994.
9. Beverly Biderman, *Wired for Sound: A Journey into Hearing* to be published in the fall of 1998 by Trifolium Books
10. In 1988, the first detailed report of surgical complications of cochlear implant surgery indicated 55 complications out of 459 implant operations, yielding an overall incidence of 11.8%. The most common problem was infection of the cut skin flap behind the ear. N.L. Cohen et al., "Medical or Surgical Complications Related to the Nucleus Multichannel Cochlear Implant," *Annals of Otology, Rhinology, & Laryngology* 97 Suppl. 135 (1988): 8-13. In 1995, a report showed an overall rate of 12.2% if device failure was included, and 9.8% if device failure was excluded (i.e., leaving only surgical complications). R. A. Hoffman, N. L. Cohen, "Complications of Cochlear Implant Surgery," *Proceedings of the International Cochlear Implant, Speech and Hearing Symposium* (Melbourne, 1994), p. 420.
11. Cochlear Implant Club International, 5335 Wisconsin Avenue N.W., Suite 440, Washington D.C., 20015-2003. www.cici.org